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## **Entering a world with no future. A phenomenological study describing the embodied experience of time when living with severe incurable disease**

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## **ENTERING A WORLD WITH NO FUTURE**

### **A phenomenological study describing the embodied experience of time when living with severe incurable disease**

#### **Abstract**

This paper presents findings from a phenomenological study exploring experience of time by patients living close to death. The empirical data consists of 26 open-ended interviews from 23 patients living with severe incurable disease receiving palliative care in Norway. Three aspects of experience of time were revealed as prominent: 1. *Entering a world with no future*; living close to death alters perception of and relationship to time. 2. *Listening to the rhythm of my body, not looking at the clock*; embodied with severe illness, it is the body not the clock that structures and controls the activities of the day. 3. *Receiving time, taking time*; being offered not asked for help, is like receiving time that confirms humanity, in contrast to having to ask for help which is like taking others time and thereby revealing own helplessness. Experience of time close to death is discussed as an embodied experience of inner, contextual, relational dimensions in harmony and disharmony with the rhythm of nature, environment and others. Rhythms in harmony provide relief, while rhythms in disharmony, confer weakness and limit time.

**Keywords:** Experience of time. Palliative Care. Embodied. Rhythm. Phenomenology. Health worker-patient interaction.

## INTRODUCTION

Time has been a major subject of philosophy, religion and science. However, defining time in a non-controversial manner, applicable to all fields of study, has consistently challenged the greatest scholars. Time may seem like air, we cannot see it; nevertheless it is still a condition of our existence. In everyday life there is a tendency to overlook the basic aspects of our existence such as time. Serious illness changes this attitude. Our time is neither solely the time of the clock, nor of the soul, or the circadian rhythm, but also a matter of significant social importance. It has economic value as well as personal value, due to an awareness of the limited time in each day and in the human lifespan (1). Even if we all relate to time, it still seems like St. Augustine's (p.354-430) famous quotation "*I do know what time is, but do not know how to put what I know into words*" (2), is relevant. According to Cicely Saunders, founder of modern hospice movement, time is a question of depth not of length (3, 4) (p105). Human life is misunderstood if there is only an interest in the number of years, Certainty of death reveals the meaning of time, (p.40, 57) (5). The healthcare system's unilateral focus on clock time (6) has given motivation to explore the diversity of time, particularly the embodied impact of time when living with severe incurable disease close to death (7).

## BACKGROUND

Palliative care is an approach to care that seeks to improve the quality of life for patients and their families facing challenges associated with living with a life-threatening and life-limiting illness. This is achieved through prevention and relief of suffering by means of early identification; thorough assessment and treatment of pain and support with other, physical, psychosocial and spiritual needs (8, 9). Palliative care is associated with an expectancy that the patient may die within the next 6-12 months (10). The science of palliative care has undergone rapid developments (11-13), however, there is little research focusing on patients lived experience of time when death is expected. According to Rasmussen & Elverdam (14),

the experience of time is under-researched and theoretically underdeveloped within nursing and in the field of nursing research.

### ***Literature research***

Literature was found in the databases PsycINFO, Medline, Pubmed and Chinal by searching headings and abstracts with the following keywords: Time, Patient, Terminally ill patients or palliative care or hospice or death and dying. There was no time limitation on the search. In addition manual searches were performed through reference lists of relevant books and articles. Five papers, focusing directly on the experience of time (7, 14-17) are included, in addition to papers discussing experience of time when living with chronic or severe illness (18-29). Previous research is divided into the following categories; individual, relational and contextual experiences of time.

### ***Individual experiences of time***

When a life-treating disease is diagnosed, patients find their sense of time, for example passage of days and view of the future altered (7, 14, 28, 29). Confrontation with death may results in a loss of the future, making the individual more conscious of the importance of living in and for the present moment. Therefore, time takes on another meaning, redefined as temporality (14). The experience of time is divided into the period before or after the diagnoses or into periods before the health problems occurred and finally the period when the individual has learned how to deal with everyday life situations. This can be reformulated as negotiating time, reflecting insufficient time and rationalizing time (14, 15, 26). The time between life and death is like balancing between time to undertake life tasks and time left to complete them. There is also an inner perspective of time relating to the body, and an outer perspective of time relating to the surroundings (21, 26). The inner time enclosed in the body

dominates when the prospect of death is present (17, 22, 23, 29). The past and the future of time are hardly present when the present time is flooded with bodily problems such as pain fatigue, nausea, and other symptoms (29). In a situation of severe illness self-care, daily routines and sleep gradually take more time, creating a need to slow down, limiting participation in other activities (15, 29). The need for a flexible rhythm between routine and novel activities is essential for retaining a sense of connection to normal life (15, 16, 24).

### *Relational and contextual experiences of time*

Time is of crucial importance within palliative care. When clock time, (a reading of a point in time as given by a watch), is sufficient, it co-exists in harmony and runs its course without dominating spaces and people, enabling the health worker to pace the care in response to the needs of the individual. When clock time is insufficient, the health workers structure their time and tasks according to a fixed rhythm of routines and rules, being preoccupied and single minded with the task in hand. This can mean that the health care workers become blinkered or almost 'blind' to the patient's appeals, with an attitude of looking without seeing and hearing without listening (25, 30).

During the disease trajectory patient and relatives are living in a waiting mode where life is put on hold. Experiencing situation of uncertainty, they may be in a fighting, surrendering or adjusting mode, making the best out of every situation (16, 21).

### *Theoretical perspective*

The theoretical perspective of this investigation is influenced by the literary work of the Norwegian nurse and philosopher Kari Martinsen (6, 31-36), and inspired by different philosophical descriptions of time rooted in phenomenology. In phenomenology one seeks to understand the conscious experience of whatever is "given" by going straight to it, as it

appears in all its diversity and complexity (37). According to Husserl, founder of modern phenomenology, natural knowledge begins with the immediate awareness of the world (7, 38), trying to put the validity of one's own presuppositions into parentheses or aside. Exploring time involves the most extraordinary contradictions, because it means exclusion of every assumption concerning objective time (39). Heidegger (40, 41) adds a hermeneutical dimension to time by emphasizing that we always live in a context. Being in time cannot be separated from the world; being-in-the-world is time itself. Usually we are prospective in our way of being; encountering death, being is given the ultimate encounter with itself. Merleau-Ponty (42) highlights that we are embodied being-in-the-world, realizing ourselves through the body (43). Perception and representation are not given content or form by an autonomous mind but by the acting body itself in the course of its ongoing purposeful engagement with the world (44, 45). Time is a dimension of being (42) understood as coming to be (46). The ambiguity of being-in-the-world is translated by the body, and understood through our relation to time. By considering the body in movement we can see how it inhabits time, for example the mobility of the older person may be compromised, reflecting the passage of time (42). According to Løgstrup (47-50), we are inlaid with breathing and metabolism in the cycle of nature (47), in dependence on each other (48). Time has its origin independently of our consciousness and existence. Our existence is bonded to a time that rapidly moves towards annihilation (49). No certainty is greater than the fact that we will die, but not knowing when gives relief from the burden of death and provides freedom to our imagination of a future (50). Martinsen refers to Heidegger and Løgstrup in relation to time and care (6, 31, 34-36). Time, vulnerability and care are related (35). Care is a fundamental precondition for life and a trinity of relation, practice and moral action (31). She emphasizes the importance of seeing the patients with the 'eye of the heart' (34). Today the rhythm of care is in a conflicting relationship with modern medical culture, where time seems to be splitting up (36).

## **STUDY AIM, DESIGN AND METHOD**

The aim of this study was to describe the embodied experience of time when living with severe incurable disease. A phenomenological approach was used to capture the experience of time, requiring an open and reflective attitude in order to be able to describe the immediate experience that manifested itself in a variety of ways (37, 51). A qualitative interview is considered as a suitable for patient receiving palliative care (52). By using unstructured in-depth interviews and trying not to anticipate and limit “what is said”, it was assumed that it would be possible to gain access to the patient’s lived experience of time.

### ***Sample and data collection***

Data consisted of 26 tape recorded interviews from 23 respondents, 9 men and 14 women, receiving palliative care in Norway. Three of the participants were interviewed twice because they wanted to talk more about the subject. All but one, were diagnosed with severe incurable cancer. The physical manifestation of the disease was quite varied; most respondents were very marked by illness and mostly confined to their bed, while some were more able and mobile. The duration of the interviews ranged from 81 - 12 minutes with an average of 40 minutes. The number of interviews conducted was determined by the amount and variation of information received. The interviews were carried out during a timespan from April 2009 to February 2010.

### ***Inclusion Criteria***

The study participants were selected on the basis of meeting the following inclusion criteria:

- Having a severe incurable disease and receiving palliative care.
- Over 18 years of age, male and female.
- Clearly orientated as regards to time & place.

- Ability to manage an interview.
- Speak and understand Norwegian.
- Participants from different setting as; palliative daycare units, palliative hospital bed units, palliative nursing home units, and private homes.

**Table 1** (see separate page)

The nurse and the doctor in charge of the ward organized and screened the possible respondents on the basis of the inclusion criteria, patients were orally invited to participate. If positive response, written information was given and the signed consent form collected. Information about how many patients were asked and how many abstained from participation was not recorded. The first researcher was notified when respondents had accepted participation, and arranged directly with the participants a convenient time to conduct the interview.

### ***Ethical issues***

The study was approved by the Norwegian National Committee for Research Ethics, the Norwegian Social Science Data Service and the hospital administration. The study was conducted in accordance with the guidelines issued by these institutions and the declaration of Helsinki (53). Prior to undertaking interviews consideration was given to the possibility of adding discomfort by asking question about experience of time when living close to death. During the interviews the researcher strove to be sensitive and not cross the respondent's border for what was not okay to talk on. In retrospect, the impression is that respondents thought it was good to have an ability to reflect about their experience of time. Respondents expressed that it was meaningful to share their experiences of time if this could add knowledge and be useful in care for other patients in the same situation.



### ***The Interview***

The interview was carried out face to face in the respondent's home or at different palliative care units. Respondents from the Palliative day-care unit were interviewed in a private room allocated for interviewing. Respondents living in palliative care units were interviewed in their bedrooms. Respondents living at home were interviewed in their living room. Except for one interview, where the spouse was present, respondent and researcher were alone during the interview. After some general words of introduction, the purpose of the study and the issue of informed consent were discussed and written consent was obtained. Demographic data such as gender, age, and self-reported diagnosis were recorded. The issue of time was raised in an open-ended initial question: *Can you in your own words tell me what you are thinking when you hear the word time.* This open ended question and the subsequent responses led to further questions. Most interviews were structured by questions from a researcher followed by responses from respondents, continuing with follow-up questions and so forth. Some respondents were verbose and metaphorical in their expression while others were more tight-lipped. Some interviews were very emotional with tears and laughter. A number of themes or prompts were used; these included the exploration of duration, rhythm, quantity and quality of time and the impact of time in connection with context, care, attitude and progression of disease. These general prompts were used as necessary to maintain the focus on the topic being pursued. Throughout the interview there was a need to be alert and sensitive to the physical limitations of respondents such as breathlessness when answering questions and their ability to complete the interview.

### ***Data analysis***

The analysis has been carried out in accordance with the phenomenological method of Giorgi, which is an adaption of Husserl's phenomenological philosophy into a scientific method (55, 56). The theoretical perspective is used as an analytical tool that sheds light on the empirical

findings. Giorgi's phenomenological method consists of five intertwined steps (37, 57); these were modified and implemented as follows:

1. Interviews and literal transcriptions conducted by the first researcher, involving actively trying to shift from being habitually predisposed to being fully and attentively present to the on-going experience.
2. Reading the literal transcriptions several times, trying to get a sense of the whole through the singular expression.
3. Meaning units that were discovered or present in relation to experience of time were noted, revealing such areas as: *disease as the turning point, fatigue takes time, time is precious, time and rhythm, attitude and time, do not look at the clock.*
4. The raw data in the meaning units covering aspects of experience of time were organized and analysed thematically, and the insight was expressed in the professional terminology of the discipline, such as: *The body is concerned with rhythm.*
5. The structure and diversity of each meaning unit was described, such as: *Listen to the body, not looking at the clock.* Some appropriate quotations which highlighted the essence of the phenomena were identified, such as: *I'm so breathless, so I try to find a good rhythm of breathing.*

The analysis is not linear but consists of a movement back and forth between these steps.

The literal transcriptions, analysis and manuscript were regularly discussed and validated within the research team.

## **FINDINGS**

There were three prominent features in the participant responses despite the different individual expressions, diverse life experiences and contexts.

## **Entering a world with no future**

To receive a diagnosis of an incurable disease is like entering a new unknown world.

Suddenly the future that one has taken for granted becomes uncertain, requiring all ambitions and plans to be modified, cancelled or postponed. Losing one's future, presents itself as the bottom falling out of one's existence. That curing treatment has been exhausted and palliative care is the only option, is difficult to accept. This is because the transition to palliative care is in itself a confirmation that the end of life may be near.

*"That day you get a cancer diagnosis presented, you enter a new world".*

In this situation, time presents itself as lifetime, with an overwhelmingly concern about life expectancy.

*"The first I am thinking of about time is how much time I have left. I would say awareness of limited life has changed the most".*

Awareness of temporariness creates a sense of having very little time left for the important tasks one wants to do, where it is important to fill the days with what really matters.

*"For the first time in life I have very little time. And I have so much I should have done in the time I have left".*

To have much to do within the limited life left presented itself as something very different to the common notion of busyness related to activity and units of time. Little time in this context referred to clarifying your values and what's important and unimportant.

*"My values are basically the same, but they become clearer. When you have a lot of lifetime it is not so important what you use time on, but when life is limited, it is important to spend time on things that have value".*

The awareness of death and an uncertain future makes a shift in attitude from a prospective behaviour, to gradually being perceptually present in the present, giving the person a new sensitivity to time. In the limited lifetime left, one tries to expand the present moment by taking one day at a time enjoying the moment. The perceptually present is achieved by all

senses, giving new impact to everyday tasks, making details in the environment significant and others' relation to time apparent.

*“I carry my death with me now, and usually he's friendly. It began in early spring because I recognized that I was going to die. Death's presence makes time very precious, intense, bright and nice, with lots of colours and sounds and smells. Time just is. The clock means nothing anymore. But sometimes when I am sad, death is not friendly anymore but heavy to carry”.*

The difference between thinking about or planning the future and having to live in the “here and now” makes it difficult to meet others in a meaningful way in the present moment.

Prospective talk seemed to affirm the limited lifetime and the embodied vulnerability of the individual. Any behaviour undertaken hastily may be upsetting because this in turn confirms the individual's weakness, shutting down the opportunity to share a story or tell what bothers them.

*“My friends sat talking about, losing weight, buying clothes, holidays and what clothes to wear, typical female chat that I used to take part in. I went outside, under the excuse of something, because I could not plan a shit, I know nothing about the future. I have no future. I have only the Now. Then I noticed how vulnerable I am”.*

Awareness of limited lifetime does not necessarily imply wanting to know the estimated time that is left. To be informed about how much time may be left is unnatural and frustrating because nobody knows, not even in this situation.

*“They do not need to tell you that you have half, or at best a year left. Nobody is alike and they do not know, since they only have statistics to go by. It's the way it is told that's important, so you get to know the reality, but to get an estimated time is very difficult”.*

When living longer than estimated or expected one enters into a life that presents itself as living on overtime that is characterized by gratitude and uncertainty. This is a strange time that feels like a gift, simultaneously prolonging the uncertainty regarding how to deal with and organize the future. The uncertainty includes a concern for the family putting normal life on hold, wanting to spend as much time together as possible.

### **Listening to the rhythm of the body, not looking at the clock**

When living with severe disease the day is structured by what you manage. The condition of illness fills the attention; sapping strength and energy, making everything slow down.

Everyday tasks such as getting up and getting dressed, suddenly takes more time, making time feel as if it is going faster.

*“It is absolutely amazing how fast time goes by. And especially after I got sick, things have gone faster, I do not know where time has gone by this year”.*

Experiencing a loss of strength and energy where everything slows down makes it difficult to be punctual according to regular time. To be punctual for an appointment may become impossible. As the embodied illness progresses, and limits the opportunities for participation in normal life, the clock time loses its structural impact and importance despite awareness of the significance of clock time for others.

*“I’m not so concerned about the clock. I have it with me, but it doesn’t govern my life. It’s more for the others to come. More or less, I notice that some of them are good at putting it away”.*

When living with severe embodied illness the universal functions such as breathing and digestion become prominent, highlighting the need for a flexible alternation between activity and rest, eating and drinking.

*“I have found that there is only one thing to do and that’s if I’m tired, then I sleep, if I’m hungry then I eat. I am not trying to push away something; I take it on there and then”.*

In a condition of embodied illness it is important to listen to what the body requires and have an embodied rhythm in harmony with the activity, in order to function well and relate to the environment. The embodied rhythm presents itself in relation to basic needs and functions, activity and rest, in relation to others and the surroundings, and when you are in harmony and out of synch or out of step.

*“I am concerned about rhythm. I like very much to be prepared in the morning, get me to the bathroom, eating breakfast, although I cannot eat very much. I know that my body is keen to maintain a rhythm; it somehow keeps track of things”.*

### **Receiving time, taking time**

When living with a severe illness it is challenging to ask others for help, especially if the health worker also gives an impression of being busy; it's like squeezing their time schedule.

However, if one is offered help, time presents itself as time given. For example

*“I wish that I was offered help instead of having to ask for help. For then I had received time instead of having to take others' time”.*

Receiving care without having had to ask for it tells the patient of the giver's sensitive generous heart which sees, listens and prioritizes, even though the actual task may not be particularly time consuming or comprehensive.

*“If you care you do your priorities by your heart, not by your head. That some come to you, when you are hot and sweaty, and turns the pillow without you having to ask for it means so much. It is such a small thing to do, but it's great to get a cool pad in the neck. Some see it, others do not see it”.*

Respondent instantly read the health workers or relatives' relation to time in movements and the way people are acting. Busyness related to clock time is often revealed through attitudes and lifestyle of individuals. A busy attitude makes it harder to share a story.

*“It's not just in health workers, but also my husband when he comes in the afternoon. I notice the time in his body language, if he is stressed or not stressed. I see it long before the words. I see it as soon as he arrives. So now and then I tell him: you can first take a walk in the park”.*

It is the embodied illness that makes everything slow down, demanding a slow rhythm in care encounters. Care in harmony with the patient's embodied rhythm presents itself as given time of relief and comfort, releasing strength from within the patient seemingly making the impossible possible.

*“I have not been on my feet for several weeks and then suddenly I manage to stand and it has been fantastic. And it is because I have confidence in the physiotherapist. I did not feel I needed to hurry and I did not get short of breath. It went incredibly well. It's amazing”.*

A rhythm off beat can impede the patient's time reinforcing the patient's sense of vulnerability and helplessness, while a rhythm in harmony has the potential to extend the patient's experience of precious time.

## **DISCUSSION**

The main finding of this study is that time is an embodied experience, given form by the acting body in the course of its ongoing engagement with the world (44, 45). It is not the clock that stops ticking but the heart that stops beating, when lifetime is ended (58). In this section the finding and the concept of time will be discussed, referring to this as an embodied three-dimensional experience of time, overlapping but with distinct elements: inner, relational and outer (Figure 1). The discussion is based on a phenomenological understanding of time as an embodied “being-in-the-world” where theoretical perspective and previous research are used to illuminate the findings.

**Figure 1** (see separate page)

### **Embodied inner experience of time**

Encountering death is described as the core experience of time (40-42). Living with severe incurable illness, our respondents redefined time as ‘life’. In an embodied condition of illness, where everything slows down (14, 15, 17), the inner perspective of time enclosed in the body dominates (7, 21-23, 26, 29). Generally, when healthy, the body is silent and taken for granted. In wellness the individual is not consciously aware of the natural tempo of their body. This is the situation for all people, young or old, as time gives the body a distinct character with regards to mobility and how signs of the aging process (passage of time) are visible on the body. Merleau-Ponty (42) emphasized that we realize ourselves through the body. If being-in-the-world is translated by a body with severe illness, and understood through a perceptual presence of embodied suffering (29), it provides a new perspective or impact of living in and for the present moment or situation (7). Our respondents felt they were entering a new world of uncertainty, entailing a new experience of busyness related to limited lifetime. Limited lifetime presents new challenges by having a new impact for the present moment, suggesting a fresh form of perceptual presence, where nature, surroundings and other people’s relationship to time was striking. Generally, we are prospective; always

thinking about the next thing we should do (40, 41) as John Lennon said (54): “*Life is what happens while you are busy making other plans*”. When lifetime is limited you lose your freedom and possibility to make other plans. However, respondents wanted realistic information about life expectancy, and some were frustrated when given estimates of how much time they might have left. This may seem like a contradiction, challenging those who have to inform patients. Løgstrup (49) suggests not knowing when death may come provides freedom of life; maybe being informed about how much time you may have left takes away the remaining freedom in life.

### **Embodied relational experience of time**

Individuals enter and inhabit each other's world, out of necessity whether they are comfortable with this or not. We live in relations and dependence upon each other and being in a vulnerable situation this dependency becomes more evident (34, 48, 59). However, autonomy is highly valued in our society, manifested through independence and performance (60). The fact that we all are dependent upon each other appears to be in contradiction to the notion of autonomy (61). Maybe that's why the patient must ask for help instead of being offered help. We believe this is a misunderstanding of the concept; autonomy is about preservation of a person's dignity. It is in how care is performed and provided that dignity of the individual is handled and safeguarded. When patients are offered help, they feel they receive time; in this their way humanity is affirmed. However, if patients have to ask for help, vulnerability and helplessness are confirmed.

Care is expressed in a cultural context which today seems to be predominately defined by productivity and effectiveness (6). This prevailing culture may challenge and threaten the opportunities of the caregivers to meet with and spend time with the dying patient. This approach means that individuals may subconsciously not be supporting patients with limited



time, since their own preoccupation with prospective time does nothing but confirm the vulnerability of the patient's life situation (25). Respondents in our study could not bear to be in situations where the focus of the conversation was on planning the future. Neither could they talk with significant others when the signals or cues communicated through their body language indicated that they were not listening or receptive to their situation or specific needs. This finding suggests, even though it is obvious, that you don't tell what's bothering you when the attitude of the person in front of you communicates busyness, or that they are distracted. Communicating is vital in the care of dying persons, and might start with really listening to what is being said (29). This observation makes us wonder whether there is a lot of missed or lost opportunity for dialogue and perhaps exploration of things that could have been said but aren't.

To be perceptually present requires an ability to tune in with the other's embodied rhythm, whether one is staff or relative, and to dare to be present without knowing or giving answers (9, 62, 63). Being in harmony with a patient's rhythm can create golden moments of comfort, such as our respondent who suddenly managed to stand again. Adopting a slower rhythm in care can provide an opportunity for the patient to open up, release energy, or share an important story saturated with meaning. In such situations, life is confirmed and patients may experience being given more time and being seen by the heart (34). However, a rhythm out of synch can be humiliating, violating the life and dignity of the individual, such as looking without seeing and hearing without listening (25).

### **Embodied outer experience of time**

The outer time can be elucidated as a contextual universal and cultural experience (7). Being cannot be separated from the surroundings (41). We are embedded in universal context of

nature and affected by its cycle and circadian rhythm (47). The cultural context is the place we are living; reflecting norms and values in a society at that time.

### *Universal time*

Nature's time appears in cycles and rhythms that continuously repeat themselves, while at the same time never returning, each day we become one day older. Life is a permanent process of breathing and digesting which reestablishes itself in a cyclic manner that rapid in a linear way moves towards annihilation (1,15,24,49,64). In the rhythms of nature repetition and change are conjoined (1). When being healthy and well the universal is taken for granted. Our respondents placed great importance on the universal cycles and rhythms, relating to the circadian rhythm of nature enabling them to keep track of things while listening to the embodied rhythm, letting it decide the day's activities. Rhythms and cycles are flexible and adjustable. When we run, the heart beats faster when we sleep, the heart rate slows down. The essence of the health-rhythms is the intertwinement, paradox and possibility, both within the body as a whole, and between the body and its surroundings (27).

### *Cultural time*

How culture relates to time characterizes the norms of a society and is expressed in the attitude of the individual. Modernity has divided time into units of time (36) and attached them to specific points of time in a linear chronological way. In our society clock time dominates the structuring and synchronizing of activities that we have to deal with in order to participate within wider society, for example when we go to work, when we eat, and times when we travel (36). In contrast to the universal rhythm, clock time is fixed like an escalator that runs at a constant steady speed. If you fail to comply with or adapt to this external temporal pattern you will be left standing outside.

To be able to relate to a fixed clock time, one must be oriented, letting it structure your activities and movements. To our respondents the cultural focus on clock time had lost its structural and synchronizing impact, even if they noticed that the clock time was important for others. Living with severe illness, where everyday tasks take longer time, the focus on clock time gave an offensive feeling of getting behind and being an outsider. Being perceptually present they could see, hear and feel other's relation to clock time, and were reflecting on busyness, as an attitude, regardless of whether one had much or little to do. Nowadays nursing is heavily influenced by clock time and conducted at a rapid pace, with emphasis on a hectic turnover or throughput of patients and ever increasing pressure to discharge early (65). In health care the professional is in a position of power in relation to their patients (66). The health worker must be aware of this asymmetry or imbalance and exercise this power by means of caring judgment (67).

The contradiction between the patient in need of a flexible rhythm, giving clock time little value, and a health care system dominated by a fixed clock time, is challenging both for patient and health workers. However, it is important to be aware that norms and values in a society are man-made and changeable.

According to Kristoffersen (27) the health-rhythms are interwoven into a web, both within the body as a whole, and between the body and its surroundings. However, rhythms create a tension between being in line or out of step, or comfortable or uncomfortable for example a feeling of comfort or discomfort when receiving personal care. The health worker should seek to facilitate the care not by looking at the clock, but by observing and complying with a starting point in the patient's embodied rhythms of breathing, digestion and sleep and rest, as this has the possibility to release comforting time. There is an obvious need for research, focused on following the patient's embodied rhythm in care and treatment.

## **Limitations**

Phenomenological research can reveal basic phenomena of importance in our lives, which can expand our horizons and allow us to see things differently. New understanding has an action potential. Therefore, the credibility of this research is related to the transparency of the method and reporting of presupposition (32, 33). Aspects of trustworthiness and transparency continually discussed within the research team included: How the interviewer's skills and ability to interview respondents living with severe illness affected the nature of the questions that could be asked and how these topics were elaborated, particularly the interviewer's fear of adding any discomfort to patients in a vulnerable situation. Furthermore, how prior understanding, the catalyst for undertaking the research, may have limited the ability to see the variations and nuances of the phenomena of interest. The research team concluded that asking respondents directly about patient's experience of time revealed central aspect of time that need to be communicated.

## **Relevance to clinical practice**

The health worker should try to tune the care and activity in harmony with the patient's embodied rhythm, for example breathing rhythm or the bodily rhythm of elimination. The health worker should offer care instead of the patient having to ask for help. If this succeeds, it has the potential to relieve suffering, preserve dignity and extend the patients experience of precious time. The health workers should be aware that they are observed by the patients. When living with severe illness most of the day is spent in a bed or a chair. Being perceptual present, from this position, the health worker's attitude and relation to time become apparent. This knowledge is important for the health workers to acknowledge and account for in their practice.

## **CONCLUSION**

The study shows that experience of time when living with severe incurable disease can be illuminated as an embodied three-dimensional model; inner, contextual, relational, with each element distinct but also overlapping. The inner dimension presents itself as life disappearing or passing faster, characterized by uncertainty and a change from a prospective view to life being lived in the present moment. In the present one tries to extend the moment, making time sensible and others' behaviours more significant. The contextual and relational dimensions, present themselves as embodied rhythms in harmony or disharmony with the cycle of nature, the environment and other persons. A rhythm in harmony provides energy and feels relieving, but a rhythm in disharmony confers weakness, helplessness and vulnerability.

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**Table 1**  
**Interviews and respondents**

Overview of participants									
Number of respondents	Interview	Interviewed second time	Male	Female	Age 42 – 88 year	Respondent receiving palliative care interviewed in private homes	Respondent interviewed in Hospital Palliative Care ward	Respondent interviewed in Hospital Palliative Day care ward	Respondent interviewed in Palliative Nursing home
23	26	3	9	14	(mean = 65 )	3	12	8	3

**Figure 1**  
**Time as an embodied three-dimensional experience with overlapping but distinct elements: inner, relational and outer**

